

THE EXPERIENCES AND RECOMMENDATIONS OF FAMILIES WITH CHILDREN WHO HAVE CONGENITAL TOXOPLASMOSIS

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ABSTRACT

*Toxoplasmosis infections are usually asymptomatic in healthy hosts, but can cause serious, sometimes life threatening, sequelae in infants when the mother acquires an acute infection during pregnancy and the parasite is transmitted via the placenta to the developing fetus. This article is part of a comprehensive research project investigating the long-term outcomes of congenitally infected children who were similarly treated for their first year of life after being exposed to *T. gondii* in the 1994–1995 outbreak in Victoria, British Columbia. Focus is on the experiences of parents with a congenitally infected child. Semi-structured interviews were conducted with parents of 10 out of 12 affected families. Results contextualize the familial experience of congenital toxoplasmosis and outline the perceived long-term physical and psychological effects. Recommendations are offered to help communities better manage the needs of similar families in the future.*

Toxoplasmosis is a disease caused by the protozoan parasite, *Toxoplasma gondii* (*T. gondii*). This parasite can be transmitted to humans in primarily three different ways (Jones, Lopez, & Wilson, 2003). *T. gondii* can be ingested orally by eating raw or undercooked meats (e.g. pork, lamb, or beef) that have been infected or through food that has come in contact with the infected meat. Humans can also inadvertently ingest the *T. gondii* parasite if they come in contact with the feces from a cat that has ingested the parasite. This can occur through contact with feces in the soil, unfiltered water, or cat litter. The third primary method is through transplacental transmission to a fetus from an acutely infected mother (congenital toxoplasmosis). Healthy children and adults with toxoplasmosis are usually asymptomatic. However, serious, sometimes life threatening, complications can result when an immunodeficient individual, such as a fetus or patient with HIV, is infected.

Congenital toxoplasmosis is worldwide in distribution, but prevalence of infection varies based on geographic location, culinary practices, and hygiene standards. It has been difficult to accurately assess the incidence of *T. gondii* infection in Canada and the United States as prenatal and neonatal screening for congenital toxoplasmosis are not routine practices in these countries (Remington, McLeod, Thulliez, & Desmonts, 2001). Researchers have estimated that congenital toxoplasmosis affects about 1 in 10,000 live births in the United States each year (Remington et al., 2001). In contrast, ' . . . prenatal serological screening to detect maternal infection is used in many European countries' (Dunn et al., 1999, p. 1829).

A congenital infection primarily occurs when the mother acquires an acute *T. gondii* infection during pregnancy and the parasite is transmitted via the placenta to the developing fetus. Risk of transmission to the fetus and severity of the disease depend on the timing of maternal infection (Roberts, Boyer, & McLeod, 2004). The incidence of congenital infection is highest during the third trimester of pregnancy, reaching 80% or higher when maternal infection is acquired prior to delivery (Dunn et al., 1999; Foulon et al., 1999; Remington et al., 2001). Nonetheless, maternal infection acquired later in pregnancy typically results in either subclinical or mild fetal infection (Remington et al., 2001). While early maternal infection is rarely transmitted to the fetus, it is associated with severe morbidity and in some cases, mortality. Anti-parasitic treatment during pregnancy has been shown to reduce the development of severe sequelae in infected children, but has had no impact on the maternal-fetal transmission rate (Foulon et al., 1999). Children with congenital toxoplasmosis infection are at risk for developing adverse sequelae, such as hydrocephalus, intracranial calcifications, chorioretinitis, blindness, mental retardation, motor deficits, and seizures.

Congenital toxoplasmosis often goes undetected at birth, as most infected infants do not exhibit overt clinical signs on routine newborn examinations (Remington et al., 2001). These infants, if left untreated, will almost uniformly develop clinical manifestations of the fetal disease during childhood or adolescence. Common delayed sequelae in untreated infants are impaired vision from chorioretinitis, hearing loss, seizures, motor deficits, and decreased intellectual scores over time (Roizen et al., 1995; Wilson, Remington, Stagno, & Reynolds, 1980).

Prompt diagnosis and initiation of treatment in congenitally infected children is associated with more favourable neurodevelopmental, ophthalmologic, and audiologic outcomes (Guerina et al., 1994; McAuley et al., 1994; Roizen et al., 1995; Wallon et al., 2004). Residual deficits may develop even after early intensive treatment, such as lower intellectual function than siblings (Roizen et al., 1995). Very little is known about the long-term prognosis of treated infants and the impact on their academic achievement or cognitive abilities (e.g., attention, memory, executive functions). Recurrences of active chorioretinitis or new retinal lesions may appear during childhood, adolescence, or even adult life (Mets et al., 1996; Roberts et al., 2004). For treated children with congenital toxoplasmosis, minor physical impairments may include 'mild reflex asymmetry . . . mild hemiparesis . . . and diminished unilateral fine motor function' (Roizen et al., 1995, p. 16).

Schools require information from parents and health professionals regarding the possible long-term effects of congenital toxoplasmosis in order to work more effectively with these children. Teachers need to be knowledgeable about the child's disease and the impact on the family. Congenitally infected children may present with ocular or neurological problems when they enter school, requiring appropriate adaptations and modifications to their educational plan. Educational professionals also need to monitor these children for evidence of late-onset problems as these may have an impact on academic achievement.

While delay of treatment has demonstrated an effect on the severity of complications arising from congenital toxoplasmosis, recurrence of complications remains a factor throughout the life of the child (Jones et al., 2003; Wilson et al., 1980). As a result, congenital toxoplasmosis can be considered a chronic illness given the 'permanent deviation from the normal, caused by unalterable pathological changes' (Fisher, 2001, p. 600). Research looking at the impact of having a chronically ill child on parents has demonstrated commonalities, regardless of the specific illness (Davis, Brown, Bakeman, & Campbell, 1998). Parents often report a number of physical adaptations that

must be made for their chronically ill child, including frequent hospital and specialist appointments, alterations of a child's activities, and administration of medications (Fisher, 2001; Nevile & Roberts, 1999). The psychological impact of having a chronically ill child results in parents feeling out of control (Fisher, 2001) and uncertain about the future (Dodgson et al., 2000; Katz, 2002).

In an attempt to regain a feeling of control in life, as well as for the future, parents have identified the importance of obtaining accurate and detailed information about their child's illness and maintaining a strong, supportive partnership with health care professionals (Fisher, 2001). Unfortunately, the majority of parents have reported an inconsistency and dissatisfaction with both the amount of information they are provided and their partnership with health care professionals (Fisher, 2001). Katz (2002) has suggested that this inconsistency may be due to the severity of the illness: the more life-threatening the illness, the greater the support and information parents receive. In addition, Taanila (2002) has specified that the information provided by health care professionals during the initial diagnosis of a chronic illness has a serious effect on parents' ability to cope with that diagnosis. As a result, both the timing of the information received and the severity of the illness may have an impact on the type of support that parents feel they are receiving.

BACKGROUND

In the winter of 1994–1995, an outbreak of *T. gondii* infection occurred in the Greater Victoria area of British Columbia, Canada (Bowie et al., 1997). An outbreak was suspected when health professionals noted an increase in serologically positive cases of acute toxoplasmosis infection and of toxoplasmic chorioretinitis. It was concluded that a municipal drinking water supply was the source of the outbreak. One hundred acute adult cases were identified and a screening program of pregnant women and newborns was performed.

There were 12 congenitally infected infants, all of whom were offered and accepted treatment. Four mothers were diagnosed and treated while pregnant; their infants, along with the infants of the other eight families, continued treatment after birth. Age at which treatment was initiated varied between the children, ranging from birth to nine months of age. Specialists in pediatric infectious diseases coordinated evaluation and treatment of the infected infants who completed a one-year treatment regimen of pyrimethamine, sulfadiazine, and leucovorin (folinic acid), according to rec-

ommended treatment protocol for congenital toxoplasmosis (Remington, McLeod, & Desmonts, 1995). Blood counts were monitored weekly.

In the postnatal period, 5 of the 12 congenitally infected children were diagnosed with chorioretinal scars, 3 of which had bilateral involvement. One child developed chorioretinal scars later in life (October 2000). Two children had intracranial calcifications and one had meningoencephalitis at birth.

A comprehensive, mixed-method research project was organized to investigate the long-term outcomes of these congenitally infected children. The focus of this article is to provide a comprehensive description of the experiences of parents whose children were diagnosed and treated for congenital toxoplasmosis during the 1994–1995 outbreak.

This is the first study investigating the contextual, familial impact of congenital toxoplasmosis on the parents. During the last few decades, treatment has greatly reduced the severity of congenital infection. However, questions remain regarding the long-term consequences of congenital toxoplasmosis. Parents often do not know what to expect as there is no typical clinical profile of congenital toxoplasmosis; many fear the possibility of relapses. The unpredictable nature of this illness, with a likelihood of sequelae developing later in life, places considerable stress on the family. Families may also suffer major psychological, financial, and relationship concerns. Thus, congenital toxoplasmosis not only affects the child, but the whole family. It is important to understand the context of family in the disease process. By conducting semi-structured interviews with parents of children with congenital toxoplasmosis, this article identifies the quality of life, experiences, concerns, and recommendations of these individuals in order to better educate the academic, medical, and educational communities who work with and support them.

METHOD

Given the lack of information available for medical and academic professionals from parents of children with congenital toxoplasmosis, a phenomenological-informed study (Colaizzi, 1978; Creswell, 1998; Giorgi, 1985; Moustakas, 1994; Polkinghorne, 1989; Tesch, 1990) design was used. As a result, the experiences of children and families who live with congenital toxoplasmosis and the recommendations they have for the medical and academic communities, were collected and then thematically analyzed to identify meaning and provide an understanding of the commonality within participants' experiences. This rigorous qualitative methodology was chosen to pro-

vide contextual understanding of the parents' experiences in terms of the challenges encountered and the resultant impact on their everyday life. This method allows parents an opportunity to freely share recommendations for school, medical, and community professionals in order to clarify how best to meet their child's needs and provide support for them.

Families included in the study were recruited from the original cohort of congenitally infected infants from the 1994–1995 toxoplasmosis outbreak. All 12 families were contacted for inclusion in our study. Parents of 10 of the 12 congenitally infected children (six males and four females between seven and eight years of age) were available for participation. In total, 10 mothers and 1 father participated.

Informed consent was obtained from parents and children, respectively. Each child underwent a comprehensive neuropsychological evaluation, consisting of a battery of standardized tests of academic achievement and cognition, such as intelligence, attention, memory, and executive functions. Brief interviews were completed with the parents. Assessments also included parental ratings of behavior and adaptive functioning.

Once preliminary assessments had been completed, semi-structured interviews were conducted with the 11 parents. In order to develop a comprehensive understanding of the participants' experiences, an interview format consisting of open-ended questions was employed (Roberts & Cairns, 1999). During each tape-recorded interview, the researcher posed questions to elicit information about the participants' experience with toxoplasmosis (see Appendix A). During the interviews, participants described in detail the congenital toxoplasmosis-related concerns about their children from diagnosis to present day and the difficulty experienced by their children and family because of continuous medical treatments.

Upon completion, the interviews were thoroughly analyzed using a procedure developed by Colaizzi (1978) and modified by Roberts and Cairns (1999). This procedure involved repeatedly listening to the interview tapes to gather a sense of the interviews' meanings, typing each interview verbatim, extracting significant statements from each interview transcript, and formulating statements of meaning and/or themes from these extracted statements. A theme was included if it was common to 50% of the participants interviewed, with some labeled 'less frequent' if common to 40%. Similar themes were grouped together to form clusters and labeled according to their most central meaning. Similar clusters were sorted into categories and titled based on their principal meaning.

After each interview was typed and themes were formulated, each transcript and first-level analysis was returned to its respective participant family

for their review. Each participant family was then contacted to ensure accuracy of the typed transcript and thematic representations and to gather any additional information or insight.

RESULTS

Preliminary assessments of the children looked at their cognitive, psychological, and physical development (visual, auditory, and motor). Results are summarized in Table 1. Given the types of advanced sequelae that have been observed in children with congenital toxoplasmosis, especially those who are not treated (blindness, mental retardation, motor deficits, and seizures), these complications are not considered severe. This is consistent with existing research regarding the decreased occurrence of adverse sequelae in treated children (Guerina et al., 1994; McAuley et al., 1994; Roizen et al., 1995; Wallon et al., 2004). This lack of severity may have had an impact on the experiences shared by the participants; those families with children suffering from severe or advanced sequelae may have additional or varied experiences.

Across participants, three common themes emerged: 1) effects of disease on child, 2) psychological impact on parents, and 3) interface with community. These thematic categories and their respective theme clusters are summarized in Table 2.

EFFECTS OF DISEASE ON CHILD

Effects of disease on child focused on three main clusters: eye problems, medication problems, and less frequent concerns (immune suppression and child's fear of the medical establishment). Eye damage was common to most participants with varying degree. Parents would identify that, 'She's had some eye problems . . . because that's where she's got it the most is in the one eye She told me 'I'm seeing all these things—spots and stuff' (Mother 1). While there were some concerns over the difficulties involved with taking medications, there were also some immune suppression concerns when the medications were stopped. ' . . . as soon as the medication stopped, he was very sick. Any virus any illness that went around he had. He was hospitalized a few times' (Mother 9). Given the congenital toxoplasmosis and the treatment regimes, children and parents were subject to frequent contact with the medical establishment, especially during the children's infancy. This caused additional difficulties:

TABLE 1.**Overview of Cognitive, Psychological, and Physical Sequelae in Children with Congenital Toxoplasmosis (N = 10)**

Type of Sequelae	Number of Children Affected
Cognitive Development	
Delay requiring learning assistance	2
Speech language therapy	2
Slower than peers to understand new concepts (no learning assistance required)	1
Psychological Development	
Delayed maturity compared to peers (prone to emotional outbursts, difficulty expressing emotions)	2
Physical Development ^a	
Visual Impairment	
Bilateral chorioretinitis	
Functional impairment	1
Minimal to no impairment	2
Unilateral chorioretinitis ^b	
Minimal to no impairment	3
Recurrence of chorioretinitis ^c	3
Intercranial calcifications	2
Meningoencephalitis	1

^a No auditory impairments or motor delays were reported. No hydrocephalus was present.

^b Two born with unilateral chorioretinitis; one had initial occurrence in October 2000.

^c Based on medical reports up to and including May 2004.

TABLE 2.
Themes and Theme Clusters Common to Participants

Effects of Disease on Child	Psychological Impact on Parents	Interface with the Community
Eye Damage <ul style="list-style-type: none"> • Concern with eye damage (80%) • Frequency of eye doctor visits (70%) 	Uncertainty of Initial Diagnosis <ul style="list-style-type: none"> • Stress of worst-case scenario (40%) • Lack of available information on toxoplasmosis (50%) 	Contact with Medical Professionals <ul style="list-style-type: none"> • Compassionate and responsive service (60%) • Helpful information provided from the U.S. (50%)
Medication <ul style="list-style-type: none"> • Difficulty with medication (60%) • Concerns about long-term effects of medication (40%) 	First Year of Treatment <ul style="list-style-type: none"> • Weekly visits to hospital (70%) • Employment and care-giving arrangements (50%) • Uncertainty of long-term effects on child (50%) 	Issues at School <ul style="list-style-type: none"> • Positive communication with teachers (50%) • Parental perceptions of school challenges linked to toxoplasmosis (40%)
Less Frequent Concerns <ul style="list-style-type: none"> • Immune suppression concerns (40%) • Child's fear of medical establishment (40%) 	Less Frequent Concerns <ul style="list-style-type: none"> • Long-term effects of child's medication (40%) • Worry about invasive testing of child (40%) 	Issues with Local Government <ul style="list-style-type: none"> • Need for accountability (50%) • Need for clear communication regarding cause of toxoplasmosis (50%)

Note. Percentages refer to the percentage of parents who discussed a topic.

. . . and as they got older, actually it became worse not better because now they, they got to expect, you know, the minute they saw the hospital they would cry and they knew it was time to have a blood test. (Mother 4)

PSYCHOLOGICAL IMPACTS ON PARENTS

The psychological impact on parents involved three main clusters: uncertainty of initial diagnosis, first year of treatment, and less frequent concerns (long term effects of medication and worry about the invasive testing undergone by the child). Participants identified that the ambiguity and fear surrounding their own initial experiences as parents of children with congenital toxoplasmosis were extremely stressful. Parents identified that it was 'very worrisome' (Mother 9), 'very traumatic' (Mother 10), and 'nerve wracking' (Mother 2). Not knowing what would happen, parents assumed the worst.

I had a meeting with Dr. (name) and he gave me the full 'this is what could happen,' and then it was pretty traumatic, like knowing that she could be born with defects and blindness and hearing loss. . . . So in that first week, I pretty much thought I would be raising a blind, brain damaged child. (Mother 5)

Additional stress was identified regarding the need to visit the hospital weekly, the necessary employment and caregiving arrangements required to make this possible, and the uncertainty about the future. It was unknown what, if any, recurrences of sequelae from the congenital toxoplasmosis would occur in the future.

Many also felt the effects of the lack of available information in Canada about congenital toxoplasmosis. According to one parent, upon ' . . . hearing throughout most of the process that [the doctors] didn't really have much information on this. That was scary' (Mother 3). Parents identified that family doctors, had to ' . . . flip through textbooks to answer questions' (Mother 3). Repeatedly, family doctors had to phone doctors in the United States for information. While all parents felt that their family doctors did everything they could to find information and answer questions, 'the [initial] knowledge base was not there' (Mother 3). According to Mother 5, their doctors were 'undereducated' on congenital toxoplasmosis; doctors from other countries, especially the United States and France, were more informed.

INTERFACE WITH COMMUNITY

Interface with community identified clusters regarding medical professionals, issues at school, and issues with local government. Parents' experiences were generally positive with respect to how educational institutions and the medical establishment managed the needs of their children. Parents appreciated the schools' willingness to work together with them when their children had

special needs, including the need to be flexible about time missed due to illness.

[The school has] never made an issue because right at the beginning of the school year like I said earlier, when I inform them, that, if my daughter has the sniffles I keep her home, because it's better for her immune system to have rest, rather than get fully sick, because that isn't good for her. So they've never, um, pushed that issue if she's missed a lot of school. (Mother 6)

Some parents also raised concerns about possible learning or behavioral challenges faced by their children, but were uncertain about whether these issues were related to the congenital toxoplasmosis.

Participants talked about how, for the most part, the medical professionals with whom they came into contact were helpful and understanding. For example, one parent expressed appreciation that, 'They'd get information from the States too from a doctor there who was right on top of it' (Mother 1). Parents did, however, raise concerns about how the toxoplasmosis outbreak was handled on a local governmental level.

Well, the Water Board definitely could have been more accountable. Now they do pick up—the government picked up the tab for all the medications that the children were on. But as a group of parents we wanted more than that . . . what we did want is some assurance that if tomorrow my child was blind and needed special schooling or needed things that were going to cost money that somehow that was going to be taken care of. (Mother 4)

RECOMMENDATIONS

Along with the aforementioned concerns, participants offered recommendations to help the community at large to better manage the needs of similar families in the future. Their specific recommendations were as follows:

1. Routine testing for toxoplasmosis in all pregnant women, both early as well as near the end of the pregnancy.
2. Have information about toxoplasmosis readily available for all community members, not just pregnant women.
3. Ensure that information about toxoplasmosis suggests that pregnant women as well as immunodeficient individuals filter or boil city water, wash vegetables carefully, and avoid eating raw meat.
4. Hospital staff should work to develop consistent, positive, and supportive relationships with children and families who have regular (i.e., weekly) testing for their children.

5. All health professionals, including eye doctors, need to access the most up-to-date information possible about congenital toxoplasmosis.
6. Provide affected families with all available information about congenital toxoplasmosis, note what is known and what is not yet known about the disease, and provide easy access to ongoing research results.
7. Health professionals should be more willing to answer parents' questions over the phone instead of requiring face-to-face appointments for children who are already burdened with frequent medical appointments.
8. Create and maintain networking links for affected families, as a form of support, and provide opportunities for information sharing.
9. It is important for schools to be open to two-way communication by keeping parents informed of affected children's progress and by listening to parental perceptions of their children's challenges.

DISCUSSION

Results of this study contextualize the familial experience of congenital toxoplasmosis. The participants involved in the present study experienced one of the worst outbreaks of toxoplasmosis in the world. At the time, it was the largest recorded outbreak of human toxoplasmosis and the first to be associated with a municipal water supply (Bowie et al., 1997). As a result, all participants were from a single geographic area, small in numbers ($N = 10$), and infected at the same time. These limitations need to be kept in mind when generalizing results from this study.

In addition, participants were treated promptly and responded positively. In comparison to the possible adverse sequelae noted in the literature, the present cohort described relatively minor cognitive, psychological, and physical consequences. Thus, the concerns and recommendations of these families may be minor in comparison with families with major physical sequelae. Additional research needs to be conducted with families living with a greater breadth of severity.

The parents interviewed for this study echoed similar concerns as other parents with children who are chronically ill. For the first year of the child's life, a great deal of time and effort was expended on the delivery of medications and doctor visits. The time this requires and the stress it places on the parents and the child are consistent across families with children with chronic illness (Fisher, 2001; Nevile & Roberts, 1999). However, for parents with children infected with congenital toxoplasmosis, this stress was focused

around the first year of their child's life; after that time, doctor visits became monthly, bi-yearly, and, eventually, yearly. This provided a relief that parents of children with chronic illnesses such as congenital heart failure, diabetes, or advanced kidney disorders do not receive.

While the constant stress of doctor visits and painful medication was reduced after the child's first year of life, it is important to note that the stress parents felt regarding their child's future remained. Complications arising from congenital toxoplasmosis can reoccur throughout the life of the child. In fact, several parents in this study had already reported the reoccurrence of retinal scars and vision problems. There is currently a lack of information regarding the long term effects of congenital toxoplasmosis, especially in treated children (Roizen et al., 1995). This reinforces their fears of uncertainty regarding the future. This is consistent with other families with children diagnosed with a chronic illness (Dodgson et al., 2000; Katz, 2002).

Even given the minor physical consequences, families still described experiencing a great deal of stress because of congenital infection. Initially, parents experienced stress due to the lack of information about the disease, fear of the worst-case scenario, and uncertainty over the long-term effects on the child, among other things. Some also spoke of their children's fear of the medical establishment due to ongoing treatment. When reflecting on their experiences, families described the importance of having a positive interface between families and community agencies. Medical professionals, school officials, and the local government, in particular, all have an impact on the quality of life of families with children with congenital toxoplasmosis. Given the recent reporting of contamination in the Canadian water supply, understanding the experiences and recommendations of affected Canadian families will help the community at large to effectively manage the needs of similar families in the future. As such, the results of the current investigation are particularly timely.

APPENDIX A

SEMI-STRUCTURED INTERVIEW GUIDE FOR PARENTS OF CHILDREN WITH TOXOPLASMOSIS

I invite you to share with me what life has been like since your child was diagnosed and treated for toxoplasmosis. Hopefully, through better understanding of what life has been like for you, we will be better able to care for

future children and families who experience the same illness. I will invite you to share with me anything that comes to mind, and then I will follow up with specific questions.

MAIN QUESTION:

What has life been like for you and your family since you and your child were diagnosed and treated for toxoplasmosis?

PROMPT:

At what stage did you learn about the toxoplasmosis?

If participant learned about toxoplasmosis during pregnancy then:

What was the rest of your pregnancy like?

FOLLOW-UP QUESTIONS:

What recommendations do you have for health professionals who may work with children and families in similar situations in the future? Please tell me more.

What concerns do you have for your child with regards to school? Please tell me more.

What concerns do you have concerns about your child's overall development? Please tell me more.

What recommendations do you have for teachers and school personnel? Please tell me more.

What recommendations do you have for the community in general? Please tell me more.

Do you have anything else that you would like to share with me at this time?

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